

**THERAPEUTIC CAMPS AS RESPITE CARE PROVIDERS:
BENEFITS FOR FAMILIES OF CHILDREN WITH DISABILITIES**

A Thesis

by

KYLE JAMES SHELTON

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

December 2009

Major Subject: Recreation, Park, and Tourism Sciences

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Approved by:

Chair of Committee,	Peter A. Witt
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ABSTRACT

Therapeutic Camps as Respite Care Providers:
Benefits for Families of Children with Disabilities. (December 2009)

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Chair of Advisory Committee: Dr. Peter A. Witt

This study examines the utilization of a therapeutic summer camp for children with disabilities as a respite care provider for parents of camp participants. Interviews were conducted with nine parents, from seven different families of recent camp participants at Camp LIFE, a camp for children with disabilities located in Burton, TX. The interviews were qualitative in nature, and utilized Atlas.ti research software to guide the data analysis process.

The findings centered on five areas: the daily life of a family with a disabled child, the respite needs of these families, the value of respite care in general, the value of respite as provided by Camp LIFE in particular (both while the child attended camp, as well as after the child returned home), the qualities of Camp LIFE that contributed to respite, and suggestions from parents for improvement of service provision. These findings suggest that, as has been found in previous research, raising a child with a disability is often difficult; however, this study found that none of the parents would opt to alter their situation, given the opportunity. It was also reported by parents that respite care is often hard to obtain (for a variety of reasons), but that it is a much-needed and

desired service. In terms of Camp LIFE, the interviews showed that the parents did see the camp as a source of respite care, and that each family “did something” with the time their child was at camp in such a way as to maximize these respite benefits.

This study is in agreement with an argument raised by previous research; that overnight therapeutic camps are a much-valued source of rest for many parents, and that without such respite, parents would report much higher levels of stress related to the care of a disabled child. Further research should be conducted which further examines the specific processes that allow parents to feel comfortable with obtaining respite from therapeutic camps, as well as research into ways to provide financial support and assistance to further the ability of these camps to provide such services.

DEDICATION

First off, to Mom and Dad: Honestly, I don't know where I'd be without you. You both (and you too, Dawn and Scott!) have been the basis for my being able to accomplish everything that I have made of myself so far. You always allowed me the ability to question, to think for myself; you allowed me to fall down when I needed, but you were always there to give me a hand back up. The combination of love and support you have provided me has shown me that even in the darkest days, there is light on the horizon. Without your love and confidence, I'm not sure that I would have been able to handle some of the things life has thrown my way. You never allowed me to hide from my fear or take the easy road, but forced me to face things head on. Your support is something that I will always be grateful for. I love you! I also want to thank my grandparents, and the rest of my extended family, who gave unstintingly of their time, love, and effort to help me have the best life a guy could ever ask for.

And finally, to Kimmy; you've always been my best friend, the one person I knew would be there, no matter what. I am so proud of all that you've become, including being a great Mom (I guess we know where that came from!) You always believed in me, even when I didn't believe in myself. So, with the utmost respect to my parents and the rest of my family, this thesis is dedicated to you. I often look at the picture of us in front of Hargrave, and I know your love for me is written on the frame: "More than a best friend and true confidant. Through calm or stormy weather, you will always come through." Thanks for everything, G.

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I would like to thank my committee chair, Dr. Peter Witt, for his support, upbeat attitude, and (most of all!) patience throughout the course of my graduate career. It has taken a lot of work to get me to this point, but Dr. Witt never once let me lose faith in myself, even when I wanted to. Dr. Witt, you practice what you preach: without your scaffolding, as well as your normally gentle, but insistent prodding, this thesis might never have been finished. You allowed me the space I needed to work things out, which made things take longer than I might have hoped, but you never let me get down on myself when things got rough. Thanks for always believing in me!

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To my buddies: Clay, Josh, Jake, Joel, Pynckel, Mikey, Francis, Alex, Steve, and the rest of the boys and girls (and all you MHS people, too!) – thanks for everything. Ya’ll have been there through thick and thin, and I love you guys more than life itself. Just remember, if you’re about to do something that you think might be ill-advised...what would Dad do?

To the College Station crew: thanks for the best college experience I could have asked for. This one goes out to Aaron and Dan – thanks some great times together! I know living together was probably not the “smartest” idea, but it sure was a helluva good time! To everyone else...I’ve had a blast hanging with you in CS for the last several years, and I’m looking forward to more good times to come!

To all the ’06 Talons – thanks for being such good friends, and for letting a frog feel like he was just another Talon. To Kyle Bailey – you were always supportive when I needed it, and a great roommate. Roll out...you know the rest.

To Kellie...I know you’re up there, looking down on me and giving me a big grin for finally getting this done. I’m sorry you weren’t here to see the final product! I love you, and I want you to know that a lot of this is for you. Keep looking out for me, hokay?

Finally, a big thank you to Dr. Garvin and Constantina; you supported me when I needed it, gave me room to stretch (and pushed me out of the nest when it was required!) and helped instill a belief that I would come out the other side stronger than I went in. Constantina, your support helped me get through a lot of rough times, and I don’t want to think about where I’d be without you. Thanks for not letting me give up.

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CHAPTER I

INTRODUCTION

With the advances in medical care over the past several decades, the issues regarding care of chronically ill children in a family and community setting has never been more pressing (Hamlett, Pellegrini, & Katz, 1992). These advances have enabled families to care for their children in the home as opposed to a hospital setting, which places increased burdens on the family as a unit, affecting such areas as family cohesion, conflict, and problem solving skills (McClellan & Cohen, 2007).

It is estimated that 20 to 30% of children and adolescents face a chronic illness or health condition, which often lasts indefinitely (Brown, et al., 2008). With such a large number of children needing care, it is important that these families are given as much support as possible, in order to alleviate any potential issues related to family functioning. Several studies regarding these issues have found that respite care, where the child is cared for by someone other than the parent, has proven helpful in creating a place where parents can “recharge their batteries,” spend time with their children who are not ill, or do other necessary tasks, which could range from employment to grocery shopping (Cowen & Reed, 2002; McNally, Ben-Shlomo & Newman, 1999). Jeon, Brodaty, & Chesterson, (2005) found that respite care provided several benefits, “which included time to rest and relax, freedom to pursue other activities, improved self-esteem, feeling secure about possible breakdown of care arrangements,

This thesis follows the style of *Journal of Leisure Research*.

improvement in family relationships, and sleep patterns.”

One area that has received limited research is the use of summer camps, specifically designed for children with chronic illness, as a provision of respite care. Meltzer & Johnson, (2004) reported that most of the research on these camps had focused on the benefits for the children, in areas such as treatment adherence and social networking. These authors went on to report that only one study in their review had specifically examined family functioning during and after a camp for children with cancer; that study demonstrated that maternal social interactions outside the family improved, with the change lasting for one month after the camp ended (Smith, Gotlieb, Gurwitsch, & Blotcky, 1987). Meltzer & Johnson (2004) posited that mothers would report less stress related to caregiving demands once their child returned home from camp, and that mothers’ general psychological distress would improve while their child was at camp. The study found that mothers did indeed have lower subjective stress levels for a month after their child returned home, and their levels of psychological distress were significantly lower for the week after the child returned home. The authors also stated that additional research is needed to examine whether their hypotheses hold true for other groups of chronically ill children, as well as in other domains of family functioning beyond mothers’ psychological stress. It is important to determine whether the benefits found in the Meltzer study were relevant only to that specific group of families, or if respite care at similar summer camps also extend the same benefits. The present study seeks to examine some of these areas, as well as to extend the body of literature regarding respite care and its impact on the family as a unit.

The purpose of the present study was to examine the benefits of respite care for family functioning. The study was performed through Camp LIFE, a nonprofit organization that provides summer camp experiences for children with a range of illnesses, including mental retardation, cerebral palsy, visual and hearing disorders, autism, Down syndrome, and spina bifida, among others (LIFE, 2009). A qualitative research design was utilized, including semis-structured interviews with several families of recent camp participants. Several recent studies have utilized qualitative measures with groups of chronically ill or disabled children and their families (Ainbinder, et al., 1998; Brody & Simmons, 2007; Hummelinck & Pollock, 2006).

Rationale for the Study

The study is needed in order to help ascertain some of the answers to the questions raised by Meltzer and Johnson (2004); namely, whether the benefits found in their study may be similar for other groups of parents, as well as the other areas of family functioning that may be impacted by overnight respite care services. In addition, this study will benefit Camp LIFE in that it will hopefully provide supportive evidence for the need for overnight camp services, especially in an area (family functioning) that has not been studied in depth. If evidence is found that parents do report better family functioning after their child returned home from camp, it will provide additional ammunition to make the case that Camp LIFE should continue to offer its services to children and their families. This is an argument furthered by Meltzer & Johnson (2004). These authors relate that there is financial support for respite care programs at the federal level (e.g., Lifespan Respite Care Act of 2002), as well as in over 30 states, and

through Medicaid waivers. If therapeutic summer camps are designated as overnight respite care providers, they may be able to apply for and receive funding for existing or new camp programs; the lack of funding from government agencies was cited by several respondents to this study as a reason why they were unable to utilize Camp LIFE as often as they had hoped. Finally, the study hopes provide some information that will help Camp LIFE tailor its services to maximize its benefit as a respite care provider.

The Author's Frame of Reference

I have been involved with summer camps and similar forms of youth development for several years, first as a camper and then as a counselor and staff member. I attended camp for 10 years as a child and adolescent, and then worked as a counselor for five years at several different camps. In addition, I was the Challenge Course facilitator at a camp for one summer. While none of these camps were specifically for children with disabilities, I did have the opportunity to work closely with several children with various physical and mental disabilities during my time as a camp counselor. These experiences certainly influence my viewpoint on the possible benefits of a therapeutic camp, as well as providing a lens through which I can empathize with parents who are caring for a child with disabilities. While I will try to maintain a sense of objectivity around the research for this thesis, it is impossible to remain completely objective; such is the nature of qualitative work, especially when interviewing participants. My perspective on summer camps in general is that they are positive places for youth to gain social and experiential skills; this fact seems even more apparent to me when I consider that many of the children who attend Camp LIFE may not be able to

participate in activities that non-disabled children would consider a matter of course.

Thus, the benefits of Camp LIFE seem to be of even more import than those of a camp that was not designed for disabled children. I tried to minimize this viewpoint, however, as it introduces a bias that the parents of Camp LIFE participants may not share.

Another bias that may be present are my preconceived notions regarding parenting a child with disabilities. I cannot begin to fathom the complexities such a relationship entails, so I have done my best to approach each interview with an open mind, understanding that every situation is different, and not placing judgments around any particular system. In addition, I tried to be as objective as possible about any personal beliefs about what the respite time these parents have been given while their child is at camp “should” be used for. Chapter I has provided an introduction to the purpose of this research study, and provided a basis for the framework upon which this study was conducted. Chapter II will provide a review of the current literature regarding childhood disability, its impact on family functioning, models of caregiver burden, and an explanation of therapeutic camps. Chapter III provides the summary of the methodology used to conduct this study. Chapter IV presents the results of the study. Chapter V will conclude this paper by presenting a summary of study findings, a discussion of those findings, implications for practice, and suggestions for future research.

CHAPTER II

LITERATURE REVIEW

Childhood Disability

There has been much research done in recent years that suggests that a child's chronic disability can adversely affect his or her family (Drotar, 1997; Pai, et al., 2007; Shudy, et al., 2006). Chronic illness and disability can range from mild asthma to cancer, visual and auditory impairments, cancers, intellectual disabilities such as autism and Down Syndrome, or other disorders; it is estimated that 20 to 30% of children and adolescents in this country face a chronic disease or disabling health condition (Brown, et al., 2008); a study by the American Journal of Public Health (Newacheck & Taylor, 1992) found that 31% of children under 18 had a chronic illness, or almost 20 million children nationwide. This study also found that 9% of children had an illness with moderate severity, and 2% experienced severe chronic illness. While only 2% of children experienced a severe chronic illness, this group constituted 19% of physician contacts and 33% of hospital days related to chronic illness (Newacheck & Taylor, 1992). Chronic illness can be defined as a physical, usually non-fatal condition that 1) interferes with daily functioning for more than three months in a year; or 2) causes hospitalization lasting more than one month in a year; or 3) is thought at the time of diagnosis to result in either of the preceding (Pless & Pinkerton, 1975). Quittner & DiGirolamo (1998) estimated that more than one million children in America have a serious chronic illness or disability that requires ongoing and comprehensive care.

The psychological aspect of these diseases, and their impact on both the patient and his or her family, has been studied increasingly of late. There are a few reasons that may explain this phenomena; the survival rate and quality of life for the average chronically ill child have improved greatly due to recent medical advances (Hamlett, et al., 1992), and changes in healthcare, such as deinstitutionalization and the advent of managed care, have contributed to an increase in home care for children who have very serious medical or developmental issues, yet are not required to remain in the hospital for extended periods (Sales, 2003). This, in turn moves a large part of the care for these children on family caregivers (usually their parents) who are often required to perform specialized medical tasks, take their child to the hospital for evaluations, and deal with balancing finances, family life, and both psychological and medical aspects of their child's illness (McClellan & Cohen, 2007; Sales, 2003).

Researchers have shown that there is a need for continuing study of the ways in which a child's illness places burdens on the family unit. Children are unable to provide care for themselves when they are healthy; this situation is even more exacerbated when the child is the victim of a serious, long-term disease or disorder. Children with chronic illnesses depend on their parents to provide them with food, shelter, and clothing, as well as ensuring that they have proper medical care, and social support. Parents are often required to take their children to frequent medical appointments, and in many cases are unable to make their own decisions about proper medical care and procedures. Thus, it falls to the parents to become educated about the disorder and interact with medical and other allied health personnel. In addition, parents must manage the care of any other

children present in the home, as well as allow themselves time to be “alone”, to “recharge their batteries”, free from worries and concerns about the welfare of the family. In many cases, it is this time “alone” that falls by the wayside. It is therefore important for research in this field to examine ways in which parents can be allowed to “recharge”, and thus continue to provide for their families at an optimal level. While much of the research done in this area has focused on children with a “chronic illness”, the basic principles can easily be extrapolated to children who have a disability: for example, autism, mental retardation, learning disability, or Down Syndrome.

Impact of Chronic Illness and Disability on Family Functioning

Recent research has borne out that families which include a chronically ill or disabled child are at greater risk for deficits in family cohesion, adaptability, parent-child interactions, family conflict, and problem solving skills (McClellan & Cohen, 2007). In terms of family functioning, research has shown that issues may arise in many different areas. One such area refers to maternal mental health, where the presence of a disabled child adversely affected mothers’ psychological functioning (Breslau, Staruch, & Mortimer, 1982). Other areas studied show an increase in family conflict (Pai, et al., 2007) and issues related to maternal sleep and daytime functioning (Meltzer & Mindell, 2007); significant disruptions in sleep patterns and associated problems with daytime functioning were found in this study, with both the requirement of nighttime care-giving, as well as stress related to the child’s disability, accounting for problems sleeping, depression, and fatigue. Other studies have also found a relationship between caregiving stress and decreased physical health for parents of children with a chronic illness.

(Blyth, Foerster, & Panepinto, 2006) found that mothers of children with sickle-cell disease were more fatigued, had more trouble concentrating, and reported more subjective levels of stress than mothers of children who did not have the illness, while (Brehaut, et al., 2004) found similar issues faced families with a child diagnosed with cerebral palsy. Cottrell & Khan (2005) found that mothers of children with epilepsy reported issues related to lack of sleep, which in turn led to problems with marital satisfaction and maternal health. Significantly lower levels on “quality of life” scores were reported by parents of children with cancer (Goldbeck, 2006), neuromuscular disease, renal failure and cystic fibrosis (Holroyd & Guthrie, 1986), Rett Syndrome (Laurvick, et al., 2006), cerebral palsy (Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003), as well as other chronic illnesses (Florian & Krulik, 1991). Other studies also found that a child’s disability was negatively related to the parents’ psychological health (Hauenstein, 1990; Waddington & Buschcrossnagel, 1992). Taken together, these studies suggest that there is a link between the stress of caring for a child with a chronic illness and a host of physical and emotional issues for parents.

Other studies, however, have found that family functioning may actually *improve* after the presence of a child’s chronic illness. One study found that fathers of young children with cystic fibrosis rated their family’s functioning significantly higher than fathers of healthy children (Cowen, et al., 1985). In this particular study, the fathers of children with CF were found to report less difficulty on “task accomplishment, role performance, affective involvement, and values and norms”. Blair, Freeman, & Cull (1995) found that significantly more cystic fibrosis families were rated as “good problem

solvers” than the control group. Hamlett, et al., (1992) found that there was no difference on any family functioning variables when families with a child with illness were compared to healthy control families. Barbarin, Hughes, & Chesler, (1985) found that most of their respondents indicated that the quality of both their marriage and their overall family had improved after diagnosis of their child’s illness.

Models of Caregiver Burden

Recent research has suggested that there are several different models that attempt to account for the ways in which caring for a person with a chronic illness may affect the family as a unit. According to Pearlin, Mullan, Semple, & Skaff (1990), caregiving for a family member with a serious, chronic illness or disability can cause a “profound restructuring of the established relationship can occur...caregiving, which previously might have been one fleeting component of an encompassing relationship, can now come to be the dominant, overriding component”. Pearlin’s model was designed to describe the circumstances related to caring for an elderly patient with Alzheimer’s; however, it can easily be adapted to the needs of a family caring for a child with a chronic illness. Pearlin’s model has three major components: stressors, mediators, and outcomes (Pearlin et al., 1990).

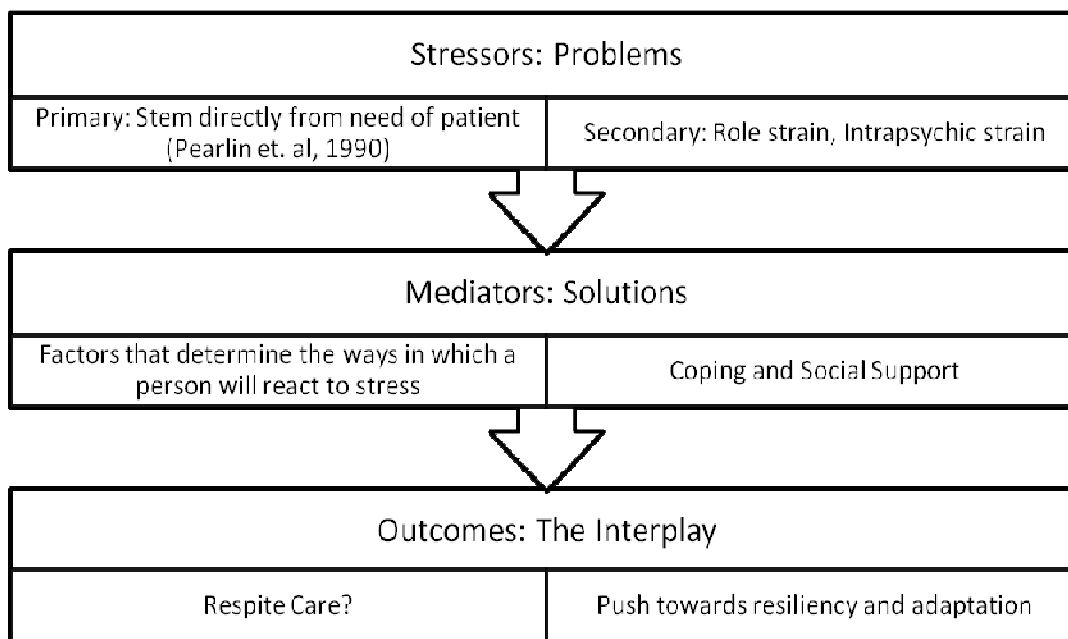
Primary stressors, according to Pearlin, are “those that drive the process that follows. By and large, they stem directly from the needs of the patient, and the nature and magnitude of the care demanded by these needs” (Pearlin, et al., 1990). Pearlin goes on to argue that these caregiving stressors lead to other stressors, which he termed *secondary* stressors. These stressors include such things as role strains (found in roles

and activities outside the caregiving situation), and intrapsychic strains (competence and gain). Secondary stressors can influence the family in many different ways; for example, there may be differences in viewpoints between caregiver and patient as to the seriousness of the disability or in finding appropriate strategies for dealing with it. Another type of strain might be caused by the amount of attention given to the person with the illness, and whether other members of the family feel slighted or “left out” from receiving what they perceive as the appropriate amount of care that they need. This may be particularly important in working with families with chronically ill or disabled children, as healthy siblings may sometimes feel that their ill sibling gets too much attention. Issues related to occupation, or monetary concerns may also play a part in causing role strain, both for the parent (who may have to take off from work to care for their child), as well as the family at large (the financial cost of care for their child, and that cost’s effect on the family as a whole). Finally, Pearlin argued that caregivers themselves needed to feel *competent* enough to care for their child, and that having competency increased their measure of personal gain or enrichment; this, Pearlin states, is “testimony to the fact that many people manage to find some inner growth as they face the severe challenges of caregiving” (Pearlin, et al., 1990).

The second part of Pearlin’s model refers to *mediators*. Mediators are the factors that determine the ways in which a person will react to stress, and are the reason why people exposed to similar stressor can, and will, react in very different ways. According to Pearlin, coping and social support are seen as the two principal mediators. These mediators can alter the reaction of the caregiver to stressful situations, and can help the

caregiver learn to focus on achieving both optimal care for their loved one, as well as be able to monitor and care for their own stress level. Therapeutic summer camps, such as Camp LIFE, can be seen as a type of mediator for the stress process of parents with chronic illness.

Finally, *outcomes* are the effects of the interplay between stressors and mediators. Pearlin relates that in social science research, these usually involve “the well-being of people, their physical and mental health, and their ability to sustain themselves in their social roles” (Pearlin, et al., 1990). In this study, we are interested in a specific mediator; that is, the respite care provided to parents of children who attended a therapeutic summer camp for children with chronic illness or disability. In addition, we are hoping to examine the outcomes of the therapeutic camp experience: what were the benefits of the camp experience for the parents, who did *not* attend camp, and whether the benefits of that respite continued to last after their child returned home from camp. Table 1 examines Pearlin’s model from a visual standpoint:

Table 1: *Pearlin Model of Caregiver Burden*

Patterson (2002) puts forth a relational view of stress and family coping that is similar to Pearlin's. Patterson was interested in why some families, when faced with a significant crisis (such as a child's chronic illness), were able to "bounce back" and competently face the situation, while other families in similar situations were unable to do so. Patterson's research suggested that families were on a "see-saw" type of mechanism, where the "demands" of the crisis were on one side, and were balanced against the "capabilities" of the family on the other, with the family's ability to adjust being the "see-saw". Patterson found that when faced with a significant crisis, there would be a discontinuity of family functioning, either in the direction of more positive functioning on one hand, or lesser functioning on the other. Patterson also discovered that this discontinuity is not set in stone for each family, or even for a singular crisis, but

that with the right benefits offered through what are termed “resiliency processes”, families can learn to adapt to and overcome significant crises, such as teen pregnancy, chronic illness, or divorce (Patterson, 2002). Patterson looked specifically at the effects of a child’s chronic illness, describing that the illness itself could be merely the beginning of a laundry list of issues for the family to deal with: the illness may beget issues dealing with medical professionals, which may lead to loss of a job, which may lead to loss of social networking and social isolation, and so on (Patterson, 2002). This theory echoes Pearlin’s theory of primary and secondary stressors, in that researchers and practitioners must be aware of the large range of effects that a child’s chronic illness can have on a family and its ability to cope effectively with other issues that may arise.

Both of these models of family stress emphasize that it is important to not focus merely on the child’s chronic illness as a stressor within the family, but rather to examine that singular stressor as the starting point for what may become a much more extended network of issues for the family at large. In a similar way, it is important to see therapeutic summer camps as not merely a benefit for the child who attends, but also for the parents and other siblings, who may also be able to benefit from the services the camp offers their disabled child.

Theodora Ooms (1996) argued that families, and especially parents, have specific roles that they play for their younger members in terms of socialization and support throughout their growth periods. This is perhaps intuitive; however, it is the need that vulnerable populations like children (and especially, disabled children) have, that makes the family unit so critically important to a child’s development. Table 2 displays the

four “core functions” identified by Ooms as critically important, as well as how they are applied in daily life:

Table 2: *Table of Family “Core Functions”*

Core Functions	How Applied
Membership and family formation	Sense of belonging Personal and social identity
Economic support	Basic needs of food, clothing, and
Nurturance, education, and socialization	Physical, psychological, social ,and spiritual development of children and adults
Protection of vulnerable members	Protective care and support for ill, disabled, or otherwise vulnerable members

Respite Care

Respite care, according to the Access to Respite Care and Help (ARCH) National Respite Network, can be defined as “temporary relief for caregivers and families caring for those with disabilities, chronic or terminal illnesses, or the elderly” (ARCH webpage, 2009). Respite care provides benefits for family members by allowing them time to “recharge”, or “take a break” from the both the physical and emotional demands of caregiving (Joyce, Singer, and Isralowitz, 1983). Botuck and Winsburg (1991) researched the use of immediate and short-term effects of planned-use respite care on 14 mothers and of school-aged and adult children with disabilities, and found that mothers

indicated that they were “happier”, with increased feelings of well-being and less depressed mood) after the use of respite services. Their research also indicated that mothers spent more time resting, sleeping, grooming, and had improved social personal care, leisure activities, and more social interactions when their children were in respite care. Similar findings regarding the efficacy of respite care have been shown in other studies, with respite care showing benefits in terms of relieving family stress (Joyce et. al, 1983; Marc & MacDonald, 1988; Rimmerman, 1989), improving family functioning and parental attitudes towards their child (Halpern, 1985), reducing social isolation, (Joyce et. al, 1983) and decreasing parental depression (Herman & Marcenko, 1997). Most of these studies have examined only in-home or day-care style respite opportunities; very few studies have examined the utilization of overnight respite care services for families of children with either disabilities or chronic illnesses. Botuck and Winsburg (1991) was one such study, which has been previously mentioned in this review has having reported positive benefits for mothers utilizing overnight respite care. The only longitudinal study of overnight respite care benefits for families of children with disabilities found improvements in psychological distress and parenting stress after 1 month of respite care use, with parenting stress levels returning to baseline 6 months later (Mullins, Aniol, Boyd, Page, & Chaney, 2002).

Therapeutic Camps

There has been a large increase in the number of therapeutic camps for children with chronic disabilities (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGear, 1990), with camps for children with burns, cancer, asthma, cystic fibrosis, mental

retardation, visual and hearing impairments, diabetes, HIV/AIDS, and many other illnesses. These camps are, by and large, operated on the same principals as a camp for children who do not have disabilities or illnesses: they allow children to experience the outdoors, and participate in activities that are “outside the norm,” such as canoeing, climbing a challenge course, boating, arts and crafts, and other experiences. However, the difference in therapeutic camps is that they are, by design, for children with illnesses or disabilities that limit them from participating even in things that children without those disabilities view as a matter of fact. Thus, staff members at these camps must always be cognizant of the specific needs of their campers, and allow each child to participate as fully as he or she is able, while still allowing for safety and comfort. The existing body of knowledge for the efficacy of these camps has shown that these camps increase disease knowledge for children with diabetes (Harkavy, et al., 1983), and children with cancer (Bluebond-Langner, et al., 1990), increased medical regimen adherence for children with diabetes (Spevack, Johnson, Riley, & Silverstein, 1989), and cystic fibrosis (Rubin & Geiger, 1991). Only one previous study, to my knowledge, has focused on the benefit of therapeutic summer camps for parents, as respite care providers (Meltzer & Johnson, 2004). That study related that these camps can, in fact, be seen as respite care providers, given that they “temporarily relieve caregivers of the daily demands of managing their child’s illness, reducing caregiving demand and improving psychological functioning while the child was at camp” (Meltzer & Johnson, 2004). However, as has previously been explained, there has been very little research on the

benefits of these camps for the families of the children who participate. It is this “hole in the literature” that the present study attempts to partly fill.

CHAPTER III

METHODS

This study was implemented to examine how families of children with disabilities who attended a therapeutic summer camp utilized their respite time while their child was away, as well as to explore some of the ways Camp LIFE could tailor its services to better serve its family stakeholders. This chapter outlines the study methods: it includes a section on trust and ethics; the context of Camp LIFE; examines study design; data collection procedures; and data analysis.

Trust and Ethics

In any qualitative research setting, but perhaps most importantly in an interview situation, it is imperative that the participants feel comfortable and at ease with the questions being asked, the interviewer, and all of the ways in which any data gathered will be used. If a participant is not at ease with the interview process or the ways in which the data will be used, he or she is likely to withhold information that might be of vital importance to the outcome of the study or, in a worst-case scenario, refuse to answer questions at all. In either case, the information obtained may become virtually useless. While this is a risk to any qualitative study, it is perhaps more so in this case, where participants are being asked personal questions about their children and their families. To help ensure that the participants were comfortable with all aspects of this process, potential participants for this study were first contacted by the director for Camp LIFE, who had previous knowledge of and a rapport with the campers and their families; however, after the initial contact, all further communication was solely between

myself and the participants. This was done to ensure that no parent felt “obligated” to participate in the study, and did so of their own accord. It was hoped that by using the director as a “gatekeeper”, who saw a benefit for the study, the participants were more likely to feel comfortable with the purpose of the study, its potential benefits for their families and Camp LIFE, and felt more encouraged to ask any questions they may have about any part of the study design before the interviews took place. To help further this inclusion, all of the interview questions were reviewed by the Camp LIFE director to ensure that Camp LIFE’s goals were being met. By giving Camp LIFE a feeling of partnership in the decision process, it was hoped that the participants would be more likely to engage in open and honest communication regarding their feelings about camp, their use of respite care, and the issues surrounding parenting a child with a disability.

Camp LIFE: Context

Camp LIFE was founded in 2004 by Texas A&M student Sterling Leija, with support and assistance from Dr. Amy Sharp and the Family Support Network, part of the Center on Disability and Development at Texas A&M University. Camp LIFE is held twice a year on the grounds of Camp For All in Burton, Texas, which has fully-accessible facilities for campers with disabilities. According to the Camp LIFE website (Camp LIFE), the camp offers activities such as horseback riding, a climbing wall, swimming, canoeing, archery, and arts and crafts, among others. The staff of Camp LIFE is made up primarily of pre-service special education majors from Texas A&M. The camp offers a one-to-one camper to counselor ratio, which allows each camper to receive individual attention and the support her or she needs to fully participate in all

activities (Camp LIFE, 2009). Camp LIFE serves children and adolescents (ages 5 to 21) with a wide range of disabilities, including autism, cerebral palsy, Down syndrome, epilepsy, mental retardation, visual impairments, hearing impairments, and spina bifida. In addition, siblings of children with disabilities are also eligible to come to Camp LIFE.

Participants

Parents were contacted by the Camp LIFE director, who knew the parents in her role as camp director. Having the parents contacted initially by the director was done so that the parents would feel comfortable with the study's design and potential benefits once they met with the principal researcher. Interviews were conducted with parents until saturation was reached in terms of identifying themes and opinions.

Study Design

This study was performed using semi-structured, in-depth interviews of parents / guardians whose children had attended a session of Camp LIFE, which is a therapeutic camp for children with disabilities. Approval from the Institutional Review Board for Human Subjects at Texas A&M University was acquired before any subjects were contacted. The camp director sent out a mass e-mail to parents of previous camp participants, explaining the rationale for the present study, and requesting their participation. Another e-mail was sent out a week later, to garner further participant support. The letter from the director asked specifically that participants contact me, instead of her, if they were interested in participating; in this way, we avoided the issue of unintended coercion, whereby parents might feel pressured to be interviewed in the mistaken belief that a choice not to participate would perhaps limit their child's ability to

attend Camp LIFE in the future. Care was taken at all steps to ensure that participants realized that they could choose not to participate, or limit their participation, at any time, without loss of the ability to send their child to camp for future sessions. In addition, all participants were told that any information they gave during interviews would be considered confidential, and no members of the Camp LIFE staff would have access to the list of parents who chose to participate. Many parents seemed not to worry if their name was used; however, several did mention that they felt more comfortable with the interview process once they realized that their information and any data obtained would be confidential. The interviews were held during the final two weeks of July, 2009. All of the interviewees were from College Station, TX; four interviews took place at the participant's place of employment, while the other three took place in the participant's home.

Rationale for Qualitative Interviews

Interviews are one of the most commonly recognized forms of qualitative research, and have been used to provide data that is both reliable and valid (Mason, 2002). Interviews are useful when the research questions suggest that people's knowledge, views, understandings, interpretations, experiences, and interactions are meaningful. In short, qualitative interviewing can be seen as "conversation with a purpose" (Mason, 2002), where the purpose is to seek out and examine the ways in which the lives of the participants are shaped by the phenomena that the research questions look to explore. The examination of the use of respite time while a child is at a therapeutic camp cannot exist without first seeking to understand the ways in which

that child's disability impacts the family as a unit, or what "time away" from that child means to the rest of the family. Thus, in-depth interviewing is a tool to examine the context of the participant's lives before, during, and after the Camp LIFE experience.

Interviews

I prepared several leading questions regarding the home life of the family, the impact of the child's disability on the family, and the family's use of respite care, both previous to attending Camp LIFE, and since the date of attendance. In addition, there were questions asking how Camp LIFE might better tailor its services as a respite care provider. The interview questions were formulated with input from both the principal investigator's academic advisor, as well as the Camp Life director. The interview questions were deliberately open-ended, in the hopes that participants would feel encouraged to expound upon anything that they felt was particularly important to their specific situation. The interviews were conducted at a time and place amenable to the participants; most were in-home, with a few during regular business hours at the interviewee's place of employment. The interviews took approximately 45 minutes to one hour to complete. Following is a list of the interview questions:

- 1) Please tell me a bit about what your daily life is like: work experiences, home/family life, and daily stressors?
- 2) I can imagine that having a child with a disability would affect your family in different ways in different ways – if you don't mind, could you talk about how that has affected your family?
- 3) How have you had to make changes in your lifestyle to adapt to having a child with a disability?
- 4) Do you feel that having a child with this disability has brought your family closer together – i.e., what positives are there that have come from this experience?

- 5) Please tell me about your opportunities for respite care, both inside and outside of the home. Do you utilize respite care? Why or why not? Are there any respite care opportunities that you would like to obtain that you have not been able to utilize? What is the reason?
- 6) Please describe your experience with Camp LIFE. How long has your child been attending? Why did you first choose to send your child to Camp LIFE? Has it been beneficial to them?
- 7) Please describe what you did while your child was at camp. Were you able to utilize this respite time in a way that was meaningful to you? Why or why not? Is there something Camp LIFE could do to help you utilize that time in a way that provides more respite to you as a parent?
- 8) What were your expectations about Camp LIFE (or other respite care), versus the reality of that respite?
- 9) When your child returned from camp, did you notice any changes in his or her behavior? Were there any changes in family life as a whole? (Ex: fewer arguments, more likely to maintain medicine adherence, more time spent together, etc.)
- 10) Is there anything else you can think of that Camp LIFE can do to help make things easier on your family?

Use of Data

With the participants' permission, the interviews were audio taped, and then transcribed. Taping allowed the interviewer to focus on the the conversation with the parents, rather than on trying to take notes and possibly interrupting the flow of conversation. Also, recording and transcribing data ensures that the extent of the interview is intact, and nothing of import was lost due to poor note-taking. In addition, I recorded fieldwork memos after each interview. This enabled me to keep track of anything that was particular to the interview, or to the participant, that might be of note when coding data.

Data Analysis

Once the interview data was collected and transcribed, I utilized one of the most popular qualitative research software packages to code and examine my data; ATLAS.ti. This program has seen wide use in qualitative research studies for several years (Lewis, 2004). The data was then be examined, as suggested by Strauss & Corbin (1998):

- 1) Interviews and field notes were transcribed
- 2) Data were microscopically examined, line by line, to develop initial categories and relationships between categories (p. 57)
- 3) Questions were asked and comparisons made to guide theoretical sampling and to consider the categories' ranges of properties and dimensions (p. 73)
- 4) Data were open coded to identify and describe concepts related to the categories (p. 101)
- 5) Data were axial coded to relate categories to their subcategories on the level of properties and dimensions in order to integrate the structure (conditional context of the phenomenon) with the process (sequences involved in a phenomenon over time) (p. 123)
- 6) Data were selectively coded to integrate and refine the theory, and to identify the range of variability and theoretical saturation of its concepts (p. 143)
- 7) Data were process coded to identify sequences involved in the phenomena, and to trace the changes in structural conditions of these sequences (p. 163)
- 8) A conditional/consequential matrix was constructed to consider the relationships between macro and micro conditions and consequences to each other and to the process sequences, while considering contingencies (unanticipated events) (p. 181)
- 9) Indicators were theoretically sampled that represented relevant concepts, and their properties and dimensions were compared until categorical saturation was achieved (p. 215)
- 10) Memos and diagrams were developed to illustrate the relationships between concepts and create the logic model (p. 241).

After the data was open-coded, the transcripts were again examined, with salient codes being placed into code "families", which included codes that seemed to fit together in a thematic way. This allowed me to re-read the transcripts to ensure that I had not missed any important information, as well as allowing me to examine patterns

within the codes of data and see how similar “snippets” of text related to each other. As my advisor and I discussed, the attempt was made to “build a story” regarding how the phenomena of raising a child with a disability affects each family, both in similar and divergent ways. To that end, I examined the data with an eye towards the ways in which each story hit upon similar themes, while remaining open-minded with the idea that each family was unique, with differing experiences and issues.

CHAPTER IV

RESULTS

A total of nine parents were interviewed during the six interview sessions. Two of the interviews included both the father and mother of the same child; another interview was conducted with two parents, one for each of two children. The interviews lasted approximately 45 minutes to one hour, and were held either at the participant's place of employment or in their home. Table 3 provides the pseudonyms for each parent, the sex and age of their child, their child's disability, and the number of times their child had previously attended Camp LIFE. All participants were given pseudonyms to protect their identity. In addition, any proper names of children mentioned in this study are also pseudonyms. The codes after quotations in the text are to allow me to trace the quotes back to the transcripts.

Table 3: *Interviewee Background Information*

Pseudonym of Parent	Sex of Child	Age of Child	Child's Disability	Number of Times Child had gone to Camp LIFE
Jeff and Sarah	Female	10	ADHD/PDD-NOS	5
Ashley	Male	6	Down Syndrome	Several
Mary	Male	11	Down Syndrome	4
Michael and Erin	Female	12	Down Syndrome	5
Nancy	Male	10	Auditory	3
Rebecca	Male	13	Autism	2
Nicole	Female	9	Learning Disability/ Central Auditory Processing	1

This study was designed to examine several different aspects of family functioning: the daily life of a family raising a child with a disability; the family's respite needs, both met and unmet (whether camp-based or outside-care based); the value of Camp LIFE in providing respite for families in need (both during camp, as well as potential benefits remaining after the child returned home); an examination of the processes through which Camp LIFE benefits families; and an exploration of possible suggestions provided by parents as to how Camp LIFE may be able to tailor its benefits to maximize services to both children and family members.

Analysis of the transcripts of the interviews with parents led to identification of five major themes. Each of these themes and related subthemes are discussed in the following sections.

Daily Life

The first theme related to the daily life of families who were raising a child with a disability. Two sub themes were indented: Family Stressors and Benefits.

Family Stressors

When asked about the daily life stressors of raising a child with a disability, parents had several different thoughts on what made things particularly difficult. Ashley, whose six-year old son has mental retardation, related that while all parents feel like they're "on the go" all the time, it is particularly difficult for her, given that her son is unable to explain his needs and desires, which forces her to "play detective:"

...we do a lot of therapy tutoring, different things to help my son ... so, I work part time right now and directly after work, my son has to be at speech therapy. We have to be at tutoring. We have a busy, hectic schedule but it's like we're never at home...Most people are getting off work and that's when I actually get

off work. I'm just not paid for that and so, healthy, optimistic....The mere fact that he does not communicate as other six-year-olds, that becomes real stressful for he and I both. Or the entire family because he'll tell us something. We don't know what he's saying. So he gets frustrated. We get frustrated. Everybody gets frustrated. [1:4 11:17, 25:29]

Ashley's comments were echoed by other parents, including Mary, who said that her son faces similar issues:

So anyway, probably with John the two major things are...would be his behavior and kind of his defiance. And then also he's got really limited verbal skills. So, anything that has to do with communicating his needs and wants and just basic communication is kind of a challenge from day to day. [3:2 40:45]

Another example was mentioned by Jeff, whose daughter has ADHD. Jeff related that for his family, the stress is felt most by his "non-disabled" children, as well as through the adaptations that are required to keep his daughter from becoming upset:

She's very much a routine child. She likes everything done in routines, which makes it somewhat harder for us. It makes any level change tough but...and it's something that we all have to deal with because even her younger brother and sister have to learn to adapt to her so they can't anger her or disturb her, put stress on her. [2:1 15:20]

Jeff gave the following example of an instance involving the importance and difficulties associated with keeping a routine:

We don't get to go out and eat in restaurants that much because of her, because she doesn't like it and because she just doesn't...for one thing, and I don't mean this in a bad way because her eating skills, table skills and that kind of thing is good but I think it makes her feel a little off [2:1 21:24] ...In a situation like that with a lot of people. Now, we did go to that reception at a wedding and she did just fine there but sometimes we'll help feed her without causing attention, drawing attention to the fact. But little things like that that we try to adapt to her to make sure that she feels comfortable, that she doesn't feel out of place. And we'll do special things for her and with the other two kids; they don't feel like we're favoring her. [2:4 25:41]

Other parents mentioned similar difficulties related to raising a child with a

disability. Mary explained that for she and her husband, raising a boy with a disability would be much more challenging if they were not able to take off from work, since their son would be unable to function in a “regular” after-school program. In addition, she highlighted something that several parents mentioned; namely that, were their children “non-disabled,” they would be participating in after-school activities such as football or soccer, that would allow their parents time to attend to daily requirements such as grocery shopping or cooking:

But like in our case, if we both work fulltime or we had to be in an office, then Clinton would need to have some type of afterschool care. And like the typical afterschool program that they offer through the school system. They do accept kids with special needs but at least up to now, he really hasn’t been able to function in that environment because of his behavior issues and his communication issues. [6:3 60-65]

Mary went onto say:

And I think, yeah, of course we didn’t expect any of this and wouldn’t be dealing with lot of this with a typical child...I think honestly for the most part, we’re trying to do everything that we would normally do. But we...I guess like maybe if any other parents had a child, 11-year-old boy at this point, that boy would probably already be very active and at in least a sport of some sort. [6:3 69:75]

Related to this, several parents explained that they applied the same rules and expectations to their disabled child as they did for the non-disabled siblings. Normalcy, or the idea that parents wanted their children to live as normal a life as possible, was a strong theme throughout almost every interview. The following is an example from a joint interview with Rebecca and Nicole. They explored their frustration with the school system, which seemed to them to be pigeon-holing their children as not being “able” to function independently.

- Rebecca: You know what? They're just like any other kids. They want to help. They don't want to be helped all the time. They want to help too. They want to feel... I met with some counselors at one of our meetings, and this was this last year, and getting them ready for high school for next year, well, what do you expect for your son? What do you want? And I'm like, that's a big question but what do you want for your child? That's what I want for MY child. I'm not limiting him. I want him to be a functioning member of society. I want the best for him. I want the very best that he can have. And he didn't know what to say.
- Nicole: The minimum that they have to do are the maximum we have to do to make you happy, yeah.
- Rebecca: I've sat in so many of our meetings and they'll go, okay now, Ms. Rebecca, the most you can ever hope is that maybe he can be in a home of some kind. And I'm like, I started off with the speech therapist. Ms. Rebecca, you can't ever expect your son to talk. And I'm like, heck, yeah, I expect him to talk. And if you're a speech therapist and you don't expect him to talk, get on out of the room.
- Kyle: Because you want to find somebody that's...
- Rebecca: Yeah! What do you mean? He has the time, he has the talent, he has all the things that... there's no physical reason. You're telling me never to expect my child to talk?
- Kyle: So you're looking for somebody that's proactive in trying to get these things done.
- Nicole: Oh, yeah. [6:32 537-560]

This example portrays the frustration many of the parents I interviewed felt regarding the stressors of parenting a child with a disability; they felt “separate”, with very few other people who understood their needs and wants for their children. It seemed that the belief the parents held that their child could, and should, be held accountable for their own life came into opposition from others, either in the community or in the school system, which directly related to the level of stress the parents felt regarding parenting. The more likely a parent felt supported by his or her community, the more likely he or she was to feel that they were able to successfully navigate the difficulties of parenting a child with a disability.

Several other parents made similar comments regarding the stressors involved in raising a child with a disability, and these examples give a common thread regarding some of the “themes” surrounding this issue. The examples given by parents seemed to be centered around the idea that it was difficult to balance care of both non-disabled siblings with disabled siblings, and the idea that there was difficulty in accomplishing daily living activities due to the need to care for a disabled child. However, along with the stressors of raising a child with a disability, parents also made a large number of comments regarding the “benefits” of raising such a child, both for themselves and for their other children. The next section will focus on what parents said was beneficial to their family as a whole.

Family Benefits

Often, people assume that raising a child with a disability is purely stressful. However, in some of the interviews parents provided information that seemed to suggest otherwise.

Several parents explained that raising a child with a disability has brought their family “closer together.” For example Ashley said:

And with Marvin, it wasn't normal. It was a lot of hard work. And so he's brought us closer together and the fact is, we take time to work with him. We take time to see what he's capable of doing. So he has taught me and my husband both to be very patient and just to enjoy life. He doesn't get agitated, like most people get mad or angry with somebody and hold a grudge. With Marvin, I mean, he's getting in trouble, 15 seconds later he's giving us a hug. [1:15 117]

Mary related that raising her son has provided more positive benefits than negative changes, because it has forced her and her husband to relate to each other and communicate effectively:

I think the ways that we've had to change our lifestyle because of Devon (note: pseudonym) are probably in the end more positive than negative. They may seem like an immediate hardship...Or it's like "I really wanted to be doing this and I'm not." But in the end, it's like they're probably changes that are better for us as individuals anyway. And then, as far as bringing us closer together, I really think so. And I think we probably would have been brought closer together with any child, but because we've had to work through so many of these issues, some of them are health related and some of them behavioral related and communication related. We do it together.

Mary went onto also discussed some of the other impacts on her marriage:

I mean, we really tackle it together. And I know that there are some couples that don't make it because of this. I'm just...in the last 11 years that I've had, I'm just hearing stories and reading things. I know that some fathers and some mothers can't handle it and so they leave. But for us, the times that our marriage where other things weren't going so well like employment issues or moving. We lived overseas for a long time trying to move back and transition back to the US mainland where there was a lot of tension in our marriage and I don't want to say that it would have gone south but it's like with Clinton, like no matter what, we have to stay together and we have to figure it out. And hopefully, anyone would say that if they had a child...But when you have a child with special needs, it just really for us, it really takes both of us sometimes. [3:08 103:115]

As a final example, Michael explained that after finding out his daughter was disabled, he went through a "grieving process", but ultimately came out personally stronger for it:

She's opened up incredible opportunities for us as a family that we would've never had otherwise...things that we do, people that we get to meet, you that, well for example, that...never would have that. Life would have been very different without her and yeah, they'd say when you have your child, when you realize she's disabled and you go through a grieving process and that's true. But then after you come to terms with that and you look at the positives of it. Yeah, it's a lot of work but I think for some of us...if you go on and look at other families, you see that they have things a lot harder than you. So don't get real quick on complaining. [4:12 341:345]

These examples illustrate that while families of children with disabilities do experience some hardships and stressors that are unique to that situation, they are also often transformed in a powerful and beneficial way by that experience.

Respite Needs

There were three sub-themes related to this theme: Adult relationships, daily life (cooking, household chores, etc.), which included utilization of Texas A&M students, and special needs related to parenting a disabled child.

Adult Relationships

As might be expected, several parents related that time to “just be an adult” was something that was sorely lacking in their daily lives; since their children were unable to be left at home with a neighborhood sitter, or were unable to interact with peers (to attend sleep-overs, etc.), parents often felt like they were unable to ever get a break from caring for their disabled child. Ashley utilized MHMR as well as Texas A&M special education undergraduate students, to provide for respite care so that she was able to simply go out to a movie with her husband:

- Ashley: Or whatever and so, I like my respite just because if me and my husband want to go to the movies, we can...Like today, we're going to the movies. We can drop him off at day care. So, we can actually go do something like that.
- Kyle: So the MHMR respite, is...how is that? Do you take him somewhere? Do they come to the home?
- Ashley: You find your own person to come to the home. Or take him to the park or whatever....Just so you can have your quality time with your spouse, and so we do have A&M students that come watch my son...A couple of hours a week just so I can do what I need to do.
- Kyle: Because you can't just leave him alone.
- Ashley: Without having to wonder what's he's into. Or he's being so busy that I don't have that time to say ... or I can just say “go play outside” because he can't. ..My son just can't leave, and be unsupervised. And so, it's one of those, they come in a couple of hours a week and I'll go get my nails done or I'll go get my hair done and it's like something for me... And so something that's just for me where he's having fun but he's supervised and I'd take them before and try to get my nails done ..My toes done or my

hair done. It's an impossibility. It's like I don't get to rest.

Ashley concluded by noting the impact of her having a disabled child on her ability to relax:

It's like that's the relaxing things for adults and it's not relaxing if you have child with special needs specially one that's so on the go all the time that can't sit still long enough. For that half an hour to get something done. [1:18 129-165]

In short, all of the parents recognized that raising a child was going to be stressful and difficult at times. One type of mediator (which helps to balance the stressor, according to Pearlin's model), is the use of respite care. Thus, it is important that parents were able to take time to participate in activities with friends, and take care of other daily living tasks in order to not feel overwhelmed by the strain of raising a child with a disability.

Daily Life / Utilization of A&M Students

Several parents mentioned that respite care was an essential aspect of managing their daily lives. In addition, parents often referred to the quality of respite care provided through local services, many of them based at Texas A&M University. For example, Mary mentioned that most of the respite care she utilized was in short time frames, enough for her to go out to eat, or shop for an hour and accomplish daily living tasks. Mary also explained something that was echoed by almost every parent I interviewed; that without respite care, things would be much more difficult for their family:

...the city of College Station has challenger sports and...not all of these are respite but a lot of them are. A lot of them are drop-off activities where we can go shop for an hour or go out to eat for an hour. Camp LIFE is a weeklong camp. And then we also are in a respite program through the state, through MHMR where we signed up for about a year ago and we actually get reimbursed for resident funds. So we have a couple of Aggies who take care of Devon just when we need it. Like when my husband has to go to meetings and stuff and they will

actually get reimbursed for their care. So, kind of depends but I feel like for the most part that, I value all that respite so much and without it, I think we might have a lot of more problems. So it's there but we understand how lucky we are. [3:9 160-162]

Mary also mentioned that much of the respite care she received was due to the presence of Texas A&M University, and the local collegiate community:

Yeah, we do and I have to give almost all the credit to where we are and to Texas A&M University and also the city of College Station. And we really didn't know what it was going to be like coming...we both went to school here. We're both Aggies but we really didn't know coming back here how good the community was going to be for kids with special needs.. I just came back for my job. And at the time, my husband didn't have a job so...but we quickly found out mostly through A&M's Special Education Department but also Health and Kinesiology that there's always programs out there....And so, honestly, with and I-I hope this doesn't affect your study-but we're just so lucky. And I think it's because of the student population in A&M and all the programs that are set up here. [3:9 143:163]

Several parents mentioned that they felt very happy and were very "blessed" to live in College Station, given the high number of college students who were involved in community service projects (including respite care programs). These parents mentioned that if they were unable to access or utilize the programs offered by Texas A&M and other local agencies, they would find daily life much more difficult. The belief that Texas A&M and the local community was supportive of children with disabilities and their family situation also played a role in the comfort level of parents when the time came to take them to Camp LIFE. As noted in a later section, many parents mentioned that Camp LIFE's partnership with Texas A&M was a deciding factor in their decision to send their child to camp.

Special Needs Related to Disabled Children

Erin and Michael related that they had difficulty with respite care, because they

did not feel comfortable allowing “just anyone” to care for their disabled child. This was also a common idea with other parents; parents are forced to actively look for opportunities for respite care, since the general, “call the neighbor’s child from down the street to watch him” idea was unacceptable to many of the respondents. According to Michael, this lessened the amount of respite that could be utilized:

...it’s not the kids down the street that typically do babysitting. If the sub is somebody that is mature and is...and can take care of the child in the same way that you will, fine, but you tend to be overprotective anyway. And so it’s just accentuates it. So it’s, no, it is so hard to find respite even if it’s out there, they may not be what you feel comfortable about. [4:5 110:129]

Another example of special needs was one that was specific to a certain parent, but one that was echoed in differing ways by other parents, as well. Parents who were not as financially well-off faced a more difficult set of circumstances when it came to utilizing respite care; whether this was because of lack of information being provided, or the inability to pay for respite care services is unknown, but presents an interesting avenue for further study. Ashley was the only parent who stated specifically that she utilized funds and respite services from MHMR, and that she had requested funds to pay for Camp LIFE services. Ashley went on to relate that MHMR would not provide funds for Camp LIFE because it was not respite care, an argument she disagreed with:

I don’t know if there’s a way that camps can write their curriculum to what Camp LIFE actually mean because MHMR doesn’t cover it because they said it’s not respite...And everybody I talked to is like “Well, it is respite.” Because the definition of respite...I know what’s the definition of respite is. And to me, how I see it is respite. But they said because it’s not written into a format where it says it’s a respite. [1:43 489:490]

This example was interesting, because it was the only time a parent explored the possibility of using government funding to help pay for overnight respite care services; a

possibility raised as an avenue of future by Meltzer and Johnson in a 2004 journal article published exploring the specifics of family functioning as they relate to respite care.

Their study mentioned that several avenues of both federal and state funding are available to sites that are designated as “respite care” facilities, and that by becoming designated as a respite facility, therapeutic camps might be able to benefit from these sources of funding. Funding would allow these camps to perhaps provide more sessions during the year, include more activities for camp participants, or simply pass on the savings to the parents of camp participants.

In sum, parents of disabled children are, as might be expected, protective of their children, and the way they are cared for by others. Since the usual avenues of getting “a break” (such as calling a neighbor, or regular after-school programs) were unavailable to these parents, the need for respite care was strongly felt by all of the parents interviewed. This argument is echoed by several other studies of respite care needs, which found that respite services are one of the most sought-after and desired forms of care for families of children with disabilities. A national survey of respite care programs, conducted in 2001, found that almost 47 percent of respite programs have waiting lists, with 52 percent of the programs turning away families because of lack of space. There were approximately 259,000 families who are on a waiting list in 2001, with approximately 840,000 families turned away from respite services during the early part of this decade (ARCH website, 2009). These numbers include approximately 3,400 children who are turned away each week because resources to meet demand for respite services are absent (ARCH website, 2009).

Value of Camp LIFE for Respite Care

There were two subthemes related to the Value of Camp LIFE theme: The first sub-theme related to respite benefits “while” the child was at camp, and the second sub-theme related to benefits that extended to the time after the child returned home (after-camp benefits).

Respite Benefits - During Camp

Jeff and Sarah provided some information about what they did while they were at camp, which coincided with data given by all of the parents; namely, that while their child was at camp, they allowed themselves to relax, or “recharge their batteries”:

- Sarah: But still back to rest time, this spring is the first time that we actually went to that concert and the other two nights...
- Sarah: They spent the night at my parents.
- Jeff: That’s right. They got to go spent the night in her parents. We went to third day concert here so we got to...it was our date night and we got to go and enjoy ourselves and...
- Jeff: And it was really neat. And the kids, when they came back, they found out. Mommy and daddy went to a concert. They were cool with it. They got to go spent time with Mimi and Popo.
- Jeff: We didn’t have those concerns or those obligations at the time. We were able to relax. We were able to have fun. [2:32 500-550]

Mary’s comments echoed those of Jeff and Sarah, when she related that for her, it wasn’t about taking a huge trip, but instead just spending time with her husband:

So we just feel like it’s really essential for us to have that time together, and I think probably when you ask these questions, you want to hear, “we went on a week vacation to Vegas”...But we never do...We’re always...we want to stay close enough so that if something happen and it did last summer and it did with Camp LIFE, that we can always bolt and go pick him up. But...and we usually have one really nice meal out which is, I mean that alone if you’re not counting the hours of a babysitter or waiting for the babysitter to call because he did something, just having that respite. And then, a lot of time it’s just hanging around here and just enjoying each other’s company. [3:18: 310:317]

Ashley mentioned that she and her husband make sure to keep the “Camp LIFE” weekend open from any obligations, so that they can fully enjoy themselves:

And so it’s one of those...it is a big deal. It’s like we get so excited. We make sure nobody has to work the weekend....we take total advantage of it from the moment we drop him off to the moment that we have to pick him up. It’s like we only do adult things with no kids.

Other oft-given responses included time to complete household activities, like weekend projects, or to catch up on work that needed to be completed for employment situations. Nancy explained:

Because we’re not as tired and we’ve also been able to do couple things that helped us connect better strengthen our bond as parents, as a couple which then strengthens our parenting, okay. Because we’ve been able to sit up and talk without having to worry, without somebody always interrupting and that kind of thing, or we’ve been able like to think.

She went on to explain a particular instance as follows:

This last time, I forgot what it was, but there was something we needed to do on our house. And we were able to take the time at last to look at, actually look at and examine...All these different options that were available. Versus “Where did he go? Comeback here. Don’t touch that. We got to go.” You know, we’re able to take the necessary time to do that and then to talk about “Okay, let’s talk now about our summer and what are the plans we’re going to have to make” without, first of all, his input because his input is always Disney World. [5:11 201:209]

Nicole stated that for her, the benefits of respite were simply time to enjoy being with friends and family, a statement given by almost every parent I interviewed:

And so whenever we had the Camp LIFE, that was just an opportunity that was just awesome to be able to have that time to have to ourselves and not have to worry if she was going to be in a good environment or anything like that. We knew, because she was having a blast and again, just like what Rebecca said, you feel guilty, you feel like you need a break, you need to get away but then you feel like, well, like my son, the only outside activity kind of things that he does is with his family. And so you really feel that guilt but respite makes a whole difference in the world, it really does. [6:5 29]

Rebecca echoed the comment by Nicole, that being able to go antique shopping with her friend is something that she was unable to do while caring for her son, and very much enjoyed taking time to do:

Yeah. And absolutely like when they were going to Camp LIFE, Nicole and I got a chance to go antique shopping and just not... all those little things in the back of your mind when you have your kids. You know, worried. Okay, now I know I got to go find somewhere where they have chicken nuggets and fries and I've got I can't keep him out too long because he's going to just get overwhelmed and so you... That becomes such a routine in your life, you don't even realize that it's there all the time.

Rebecca also enjoyed the time she got to spend with her “non-disabled” daughter, a sentiment mentioned specifically by every parent who had other children at home:

The benefit, as far as I'm concerned, was my daughter and I got to spend some time together and just enjoy our time together, have some mother-daughter time where we were shopping and we didn't have to worry about, “Oh my God, where did my son go” because he will wander. It was just kind of relaxing. Like I said, we got to be silly and just have that time that we don't get. My son is a constant and so we just kind of got a taste of almost like normal. What a lot of other people get to do on a daily basis that they don't even take... they take for granted. [6:18 245:249]

A final comment from Rebecca sums up the general feeling I noticed from every parent I interviewed; respite care is important, no matter what you do to utilize that time:

It's great all the way around. And people that can't understand how a family can benefit from it, I just, it amazes me. And with me having the time to have that breather and to just kind of re-energize myself, I mean that makes all the difference in the world. [6:14 256]

These comments give credence to the data and research provided in the literature review, which have overwhelmingly found that respite care provides recognizable benefits to caregivers, without regard to how that time is actually spent.

Respite Benefits - After Camp

Several of the interviewees responded that even after their child returned home from camp, benefits from respite care were extended in differing ways. Often, it was in the way in which parents felt more relaxed and better able to handle the daily stressors which come with parenting a child who has a disability. For example, Nancy shared the following:

So it helped us be more patient in dealing with him. It actually helped me appreciate some of his quirks, we all have our little personality quirk. And it helped me be able to appreciate this more from a humorous perspective than from an annoyance perspective. But when there were the difficult times, I had the patience to handle it the way I needed to and not blow up or not get frustrated. And so those are such important times because it is very important that, yes, she needs to be disciplined but it needs to be in a constructive way where she can learn from it, not me getting upset with her or fussing at her. [5:12 217]

Ashley commented that because the only time her son spends “overnights” away is during camp, she very much appreciates the relaxation and recharging time, which has to last until the next time he is able to attend camp:

...we're more relaxed and for a whole weekend it's like we're out of routine which we like, because the rest of the time we get back into routine, it's okay, speech therapy, tutoring and everything. So it's getting back into our routine, where when he's gone, we don't have that....We got to be here, here, here, here and it's just for my son and nobody else. And so when he gets back, it's like, I'm good when we have to start doing speech and everything. I've rested. It's like “Okay, I've gotten my sleep.”

She went onto explain how the opportunity for respite helps her recharge:

And it's like anything else. You work Monday through Friday. You got home. You recharged and do it again...And so when he is gone I get to recharge and not only recharge because that's the only time he spends the night when he goes to the camp. The only recharge, the two weekends a year...And it's like, we're on camp count-down when camp is coming around. It's like, “Oh my God, we're about to have a weekend for ourselves.” We have to have weekends for

ourselves...It's a big deal for us because he doesn't spend the night anywhere. He doesn't go anywhere; he's at camp or with us. [1:16 110-115]

These are two explanatory examples of several parents' experiences related to parents' ability to better care for their children once they returned home, because they were able to tap into the beneficial respite they received while their child was at camp.

Camp LIFE Qualities That Contribute to Respite Benefits

A fourth theme related to the camp qualities that contributed to the respite benefits. Several parents related that they felt nervous sending their child to Camp LIFE for the first time, as these comments by Ashley regarding why she chose Camp LIFE:

When he first went to Camp LIFE, I was really nervous because he had not left the home before. So the first weekend at camp he went ... I didn't do anything. I just sat home by the telephone even though there are cell phones and cell phones go with you...I was just a wreck. But after them sending home pictures and I got to talk with the counselors and them telling me how much fun he had, it was like okay. And I did go and inspect the camp and I went up there and checked it all up to make sure.

Ashley went onto explain why she likes Camp LIFE so much:

We love the camp because when he goes, I tell other parents "You know, as soon as your child is old enough, send them to Camp LIFE. You don't understand how much fun they have." So, I like Camp LIFE. It's the mere fact that I know, my son is being taken care of. He is safe. They make sure that he is being independent because I tell him, I'm not sending him for ... as a babysitter because I want him to take responsibility.

She also reinforced the idea that camp provides her with piece of mind through providing respite care:

To me it's respite; he's having fun but he's supervised. And so that's what I see Camp LIFE is all about. And that's why I sent my son because I think of Camp LIFE as a place ...it's a lot to attend all sorts of different camps and a lot much cheaper than Camp LIFE. But my son won't be going to them because they don't take that extra step...as Camp LIFE does. [1:46 520:524]

Jeff stated that he felt comfortable sending his child to Camp LIFE because of its partnership with the Family Support Network and Texas A&M University:

Well considering that it was done through A&M, we...number one, we didn't feel as ... we weren't as leery, because we knew that she was at least in a good care. We were hoping that she would get a chance to interact with, not only the counselors, but with all the other kids that she feels comfortable with which is definitely what happens. And she's always looking forward to it for that reason I think.

Mary's statements also related to the benefits of Camp LIFE's relationship with Texas A&M, but she also mentioned that she feels comfortable with her child's camp experience because of what her son gets out of camp, in terms of life skills and experiences:

And especially with Camp LIFE just...I think the...not only the facility itself but the counselors, the Aggies that they hire. They just really make it easy for him. So that process has been really easy. I just think it's wonderful. I know that he learned so much. He learned independence skills. He learned social skills and I have seen him grow in all those ways....This is something that's happened over a number of years. But I think the fact that we send him to Camp LIFE and other camps during the summer. I really do think that they are changing a lot about him and I think probably the biggest thing is his social skills.

Mary went on to talk about some of the other things her son has learned as a result of going to camp:

I think he's learning more about how to interact in groups than even than what he does at school because they're doing so many different kinds of activities and they're actually brushing their teeth, and taking showers, and going to bed, you know. And this is something...just even showering or brushing teeth and all that stuff, basic hygiene has been a long, long process. And we'll notice when he comes back that gradually that, "No, I don't need you to help anymore. I can do it" and he can do it himself. [3:16 285:291]

Finally, Rebecca and Nicole related that they felt comfortable with Camp LIFE from the very first time they took their children to camp:

- Rebecca: I think everything I read pretty much was true to what happened at the camp.
- Nicole: And exceeded expectations.
- Rebecca: Yeah, it was... from the minute we got there, it was perfect.
- Nicole: There was nothing that was unorganized.
- Rebecca: It was comfortable.
- Nicole: They directed you and did exactly what...
- Rebecca: They kind of gave us the quick fill-in about what was going to happen. And I was just really, really comfortable with it. We got to see the dorms and they were great.
- Nicole: Well, the only thing with Camp LIFE that I think was an awesome opportunity for our kids to experience and do things that other kids get to do and...kind of just be a regular kid.

These quotes suggest that the parents felt comfortable with Camp LIFE for two reasons. First, they felt that camp provided a beneficial experience for their children, one that was enjoyable, but that also taught them valuable life skills. Camp was not simply a place to “stay and play”, but rather “fun by design”, which allowed the children to learn skills, interact with others, and gain experiences in which they otherwise not have been able to participate. In addition, participants felt that their children would be “safe” at camp, and that there was a structure and scaffolding in place in case of an emergency. Several parents mentioned that they went and viewed the camp first-hand before allowing their child to attend, and all of the parents felt that it was clean and comfortable, and that the camp administration was competent and easy to contact if needed. The belief that their children would be absolutely safe in the hands of Camp LIFE staff allowed the parents to enjoy their respite to its fullest potential.

CHAPTER V

SUMMARY, DISCUSSION, AND IMPLICATIONS

Summary

There is a dearth of research in the area of family functioning, as it relates to respite care provided to families of children with disabilities. The focus of the present study was to further the body of knowledge in examining the ways in which therapeutic camps provided respite care to parents and families of children with disabilities; to explore the daily life stressors and respite needs of family caregivers; to examine the respite care benefits provided by Camp LIFE, and to examine the processes through which Camp LIFE helped parents feel comfortable utilizing this form of respite care.

Parents indicated that they did, as might be expected, feel stressed at times from the requirements of daily caregiving for a child with a disability. Several parents related that the inability to “take a break” was a major stressor; that is, that because of their child’s disability, they were unable to take care of other daily activities, such as shopping and home chores. This may help to explain why every parent interviewed had nothing but positive comments regarding the need for respite care, and thankfulness for the opportunity to utilize opportunities like Camp LIFE.

The need for respite care services was similar for most of the parents interviewed, and related to the stresses placed on their lives by caring for a child with special needs. Several of the parents stated that they utilized daily respite in order to perform the most basic of daily living tasks, such as grocery shopping and gainful employment. Other uses of respite were that it allowed the parents time to spend time

with their other children, or simply to “do adult things”.

Camp was viewed as a valuable asset by all of the parents interviewed, with benefits of respite for several parents extending for a few days after the respite period ended. Most parents related that once their child returned home, they got back into “the routine”, and the peace and relaxation they felt while their child was gone returned to baseline; however, if there were no lasting benefits (even if they are just memories of how that time was utilized), then respite care would not have been seen as beneficial to these parents, at least after camp was over. However, that was certainly not the case; several parents said that they looked forward to the days their child spent at camp with anticipation throughout the year.

Discussion

This section examines more closely the five themes that emerged from this research, and explores how those themes fit into the context of respite care in general, as well as respite care provided by Camp LIFE in particular.

Daily Life

All of the parents interviewed explained that they faced significant daily challenges when parenting a child with special needs or illness; these statements lent more weight to findings that have been confirmed in a number of other studies (e.g., Ainge, 1995; Tunali & Power, 1993; Wilker, Hanusa, & Stoycheff, 1986). It is also, as one study noted, not inconceivable that the stress some parents may experience as a result of caring for a child with developmental disability could be disruptive to family functioning, leading to family breakdown and ultimate institutionalization of the child

(Blacher & Bromley, 1990).

At first glance, the parents in this study seemed to fit within this framework. Parents often explained that difficulties arose because their children were behind their peers developmentally. For example, where a non-disabled 11-year-old boy would be able to walk himself down the street to a friends' house and play, or attend a sleepover party, the children of these parents are unable to function in that way. Thus, the requirement falls on the parents to always remain "on the lookout" for their child's safety, as well as actively working to maintain an appropriate level of activity for their child (once again, a non-disabled child would most likely be able to do this on his or her own, or at the least explain his or her needs in a way that their parent can meet those needs in a timely manner). This need to always be "on the go" was one mentioned by almost every parent; Jeff said that parenting a child with special needs made things more difficult in that, "we have three kids but it's like raising five" [2:12 515].

Several parents related that they were very glad I asked them about positive changes that had come about from caring for their disabled child, and indicated dismay that other adults often viewed them (the parents) with pity or dismay at their circumstances. The desire to raise their children as "normal" as possible, given their particular limitations, was an overarching theme throughout these interviews, with many of the parents stating that it was Camp LIFE's emphasis on life skills, and the staff's belief in the child's ability to be as independent as possible, that made them choose to send their children to Camp LIFE in the first place. None of the parents who were interviewed indicated anything but happiness with the fact that they had a disabled child,

and in fact a couple made mention that they felt “blessed” by the opportunity to love a child with special needs.

In addition, almost every parent felt that their child brought something “special” to the world. These strong feelings regarding the love and joy they felt in their child’s presence appeared to overshadow the fears and stress they felt about parenting a disabled child, and each parent seemed to want to focus more on the positives related to their experience, as opposed to the negatives. These data are surprising, given the amount of information in previous studies that has found that parents of chronically ill or disabled children are more likely to show depression and other symptoms of stress-related experiences (Hauenstein, 1990; McClellan & Cohen, 2007). It is unclear why these parents reported none of the increased levels of depression or other issues that have been seen in previous studies. However, all of the parents interviewed seemed to be quite content with their life experiences. This would be an interesting area of further study. For example, research could be done to ask parents whether they had consulted a mental health professional for issues related to the stress of caregiving. In addition, the parents in this study were self-selected, in that they initiated contact with me in order to set up an interview. This self-selection may have necessarily limited the respondents to the parents who felt most strongly about raising a child with a disability. In addition, interviews are performative, in that participants often give “socially acceptable” answers when asked questions face-to-face. Further research might allow for observation reports and field notes, in order to explore the family dynamic in as “normal” a setting as possible.

Need for Respite Services

All of the participants in this study reported a need for respite care, with the lack of such care being an overarching theme throughout every interview. The reasoning for this need was similar in almost every case. Most of the participants seemed to feel that there just were not “enough hours in the day” to get everything done, which left them feeling overwhelmed at times. The use of local respite services, such as those provided by Texas A&M University or MHMR, was seen as essential by some; however, the supply of those services seemed, to most parents, to be unable to meet their demands. An explanation of possible solutions to this problem is beyond the scope of this study. This viewpoint does highlight the facts given earlier, however. There is a very large demand for these services, and respite care is a highly-sought-after form of service for parents of children with special needs or illnesses. The extra time and stress placed on parents who have a child with special needs was something that was referred to time and again in these interviews; thus, it would follow that the need for respite care is greater for those parents with these children than on parents whose children are non-disabled. The reasoning behind this was similar for most of the parents who expressed such a desire; their children require more than the average “neighborhood babysitter” can provide. Thus, it falls to parents to juggle daily living activities with taking care of an active, disabled child, or else to search out acceptable alternatives, such as those provided by outreach programs at Texas A&M. Several parents mentioned that without the local services provided by A&M, daily living would be made much more difficult. All of the parents interviewed for this study live in the Bryan / College Station area;

however, there was a great deal of disparity in the utilization of respite care services. Rebecca, who works for Texas A&M, related that even though she is on campus, she has been unable to find acceptable respite care services: “Thirteen years. I’ve been at this university and around students, around all the kinds of information that... I mean I’m accessible. If it was out there, I would have seen it. It’s just not, it’s not in the right places [6:212]. Other parents, on the other hand, utilized several different types of daily respite provision. The need for this type of care, however, cannot be overstated; every parent interviewed mentioned that they found it very important to have some type of respite care support. It is interesting to note here that, contrary to my belief before beginning this study, none of the parents interviewed stated that they went on vacation while their child was gone. The reasons for that are unclear; however, even when the respite provided is simply time to “recharge”, or spend time with one’s other children, respite care is considered a necessity by all of the parents interviewed for this study.

Value of Respite Care

All of the parents interviewed had similar comments regarding the benefits of respite care provision in general, and of Camp LIFE specifically. Each parent mentioned some aspect of respite care that was important to him or her; however, the overarching theme with their usage of this time is that they got to be “normal”; sleep in on Saturday, take their children out to a movie, have dinner with friends, or work on weekend home improvement projects. The lack of “normalcy” was referred to several times by parents when asked what they did with their respite time; for example, the ability to go out and have a quiet dinner without worrying about one’s child becoming overstimulated and

anxious. As was related in the previous section, other parents felt being able to spend time with other children was of great importance, because they often felt that their “non-disabled” children got short shrift when it came to enjoying time with their parents. This relates back to the need for respite services, given the daily stressors of raising a child with a disability; not ever having enough time to do everything that must be done.

As was explained by Pearlin’s (1990) model of caregiver burden, the interplay between stressors and mediators is what ultimately forms the outcome for each individual, and it is quite clear from these interviews that the mediator of respite provision is something that cannot be overstated. The respite time was not utilized in any seemingly important way; no parents mentioned taking a trip, or even that they left the Bryan / College Station area. However, the use of that respite to get back on track with daily living, as well as to recharge their batteries for when their child returned home, was something that every parent seemed to find of great importance. This importance was further highlighted for those parents who were unable to make use of any other overnight respite care services during the year; for those parents, Camp LIFE represented the one or two times a year they were able to be totally free from their caregiving obligations, and they seemed to do everything possible to ensure that they were afforded that single opportunity. As Pearlin’s model states, stressors may take many forms, including monetary issues, inter-family strain (non-disabled siblings feeling slighted), parents feeling incompetent as caregivers, and among other issues. Respite services such as Camp LIFE seek to balance those stressors by giving parents “breathing room” and allow them to get their lives back on track. This process may be different for

each family. One couple, for example, may take their non-disabled children to Sea World, while another might work through the weekend on past-due employment or household projects. Whatever form the respite takes, it is a break from the norm, a chance to catch up on things that have been put aside because of stressors related to daily living and parenting a disabled child.

Respite has consistently been seen as a beneficial part of family life, and this viewpoint was upheld by this study, as well. Without rest, parents begin to grow weary and feel overwhelmed, and the see-saw balances towards an overload of stress. When parents are allowed a chance to relax and be free from caregiving duties, however, they are able to view their life and its attendant stressors with a more focused frame of mind. This helps parents to avoid the feelings of incompetency that might arise if they were “always on the go”, without any sort of end in sight. As several parents said, they look forward to Camp LIFE all year; it provides them with a goal to reach, and helps keep stressors in perspective. Thus, once the child returns home from camp, the parents are rested and ready to again take up the daily life of raising a child with a disability. These outcomes are beneficial to both the child and parents, as well as to the rest of the family. The benefits of respite care are also proven by Patterson’s model (2002), in that it offers parents a way to become more resilient in the face of stressors related to the challenges of raising a child with a disability. Parents may easily become overwhelmed by stress if they feel that they are alone, or have no way of obtaining any help to better their situation. Here, therapeutic camps such as Camp LIFE offer both respite from daily caregiving activities, but also the idea that there are people out there who do care about

your family and how you are coping with stress. This simple idea that “we are not alone” can be a powerful tool in helping parents learn to navigate raising a child with a disability.

Along with the respite benefits parents received while their child was actually at camp, a few parents mentioned that they noticed that once their child returned home, they were more likely to be patient with their child, and were better able to deal with unexpected issues, as Ashley related: “I don’t have to run and run in the yard and to the park and everywhere for at least three or four days. So that’s like, he wants to just relax...which is if he’s relaxed, we all relax” [1:36 386]. Nancy also mentioned that she was less apt to be “annoyed” with her son after his return from camp: “So it helped me to be more patient in dealing with him. It actually helped me appreciate some of his quirks...and it helped me to appreciate this more from a humorous perspective than from an annoyance perspective” [5:12 217]. These “after-camp” benefits did not last for an extended time after their children returned home, but as was previously mentioned, if there was no lasting benefit (even if it is just the memory of a relaxing weekend), then there would be no desire for respite care services. The need for respite care, as evidenced by the parents interviewed in this study, is that respite (in whatever form it may take) is an integral part of maintaining positive family functioning. The respite benefits provided by Camp LIFE seemed to be greater than those of simple day-care, or drop-off activities; one suggestion for this is that the respite benefits are of longer duration, which necessarily increases the overall feelings of relaxation and “time to get other things done”, such as household projects or gainful employment. Camp LIFE

provided parents with the ability to participate in a host of activities that they were normally out of reach, such as sleeping in, going shopping with friends, taking care of other children, or merely “being silly”.

Camp LIFE Qualities

This study looked to examine the processes that allowed parents to feel comfortable with their respite opportunities; Camp LIFE, according to these interviews, is viewed as being a program that fosters children’s ability to be independent, work on life skills, and have fun in a safe, non-judgmental space. The explanations given by parents as to why they were able to fully embrace and enjoy their respite experience seemed to flow from their belief that camp was a place for their children to learn and have fun; however, what seemed to be of most importance to these parents was their child’s safety, both mental and physical. Several parents referred to the safety of Camp LIFE’s facilities, as well as the professionalism of its staff, as reasons why they felt comfortable sending their child to this particular camp. Several parents explained that they had either attended camp as a family, during a weekend experience, or that they had gone to camp with their child and had closely scrutinized the workings of both the camp’s facilities and its staff members. According to Ashley, she had considered several other camps (which were less expensive than Camp LIFE), but ultimately chose this camp because she felt that her son would have a good time in a protected atmosphere:

And that’s why I sent him because I think of Camp LIFE as a place and it’s a lot to attend all sorts of different camps and a lot much cheaper than Camp LIFE. But he won’t be going to them because they don’t take that extra step, as Camp LIFE does. I want him to go to learn something and he always seem to learn, even if it’s just learning to be more patient and slow down. He always comes home learning something different, something new and maybe it’s just being a

little bit more patient with us or with himself, where he doesn't get so frustrated. I see that as a positive thing. [1:47 543:548]

Jeff's comments were similar, in that his daughter enjoyed her time at camp, and felt comfortable with the facilities and the activities she experienced, which seemed to make him more comfortable, as well.

Because she gets a chance to be herself, whereas anywhere else we go, she can't do that. She's really uncomfortable in heat and that kind of thing. a clean freak for the most part. But that's a plus because she always feels comfortable there because it's always neat and clean, that she has never complained about it or whatsoever. In fact she...like I said, she always looks forward to it. And she really feels like it is her camp. She would always go, "When do I get to go with my camp? When do I get to go in my camp?" She feels like it's her camp. And so we always notice that whereas in other things that we're taking her to, wherever she's going to, she's always nervous. Like I told you, she gets sick, that kind of thing. [2:14 95]

These comments seem to suggest that there are two aspects of camp that parents find important, at least in terms of feeling comfortable enough to actually enjoy their respite time. First, they want to feel comfortable with the idea of the camp itself; its facilities, staff members, medical personnel, etc. Second, but no less important, they want their child to have fun with the activities, and to learn to be more independent and gain life skills. It is the interplay between these two concerns that came across in these interviews: each parent believed that camp would be a safe place for their child to spend the weekend, and that they would be better equipped to achieve daily life activities once they returned home. This enabled the parents to fully experience their respite, since they were not limited by worries over their child's safety. Other parents were comforted by the fact that Camp LIFE was affiliated with Texas A&M University and the Family Support Network, which gave those parents the feeling that their child would be in good

hands. This partnership with Texas A&M, along with the facilities of Camp For All and Camp LIFE, meant that these parents could drop their child off at camp and feel somewhat guilt-free about enjoying themselves, because they knew there was medical staff on site, along with “fun” activities that would occupy their child’s time. Several parents explained that the first time they took their child to camp, they were unable to fully enjoy their respite time, as they were worried about their child; however, on subsequent camp outings, they felt much more comfortable with the overall experience, and could thus enjoy their “free time” without worry. As an aside, several parents mentioned that their children had attended other camps, previous to Camp LIFE; the overall consensus was that after attending Camp LIFE, they had “raised the bar”, and would choose not to send their children to another camp after seeing the benefits that Camp LIFE had to offer their family. This belief (bracketed as it is by a parent’s desire to ensure his or her child’s safety) seems to offer compelling evidence that Camp LIFE is successfully fulfilling its goal of providing safe and memorable experiences for the children, which in turn allows the parents to feel free to utilize their respite as they see fit.

Implications

Overarching Experiences

This study, exploratory as it was, seems to provide additional evidence that furthers the basic ideas found in respite literature; in short, that respite care is not merely a welcome change of pace for caregiving parents, but that it is vital to the welfare of family functioning and the family unit as a whole. Participants in this study suggested

that, at times, they felt overwhelmed and stressed by the constant demands of caregiving, which has also been found in previous research (Drotar, 1997; Pai et. al, 2007).

However, overall, these parents intimated that rather than view parenting a disabled child as a difficulty to be shouldered, they view it as a gift to be welcomed. This is in direct opposition to research performed by Blacher and Bromley (1990), who found that parenting a child with a disability might lead to family breakdown and institutionalization of the child. Whether this opposition is due to the self-selection of the study participants (parents who chose to send their children to camp, and who chose to participate in the current study), or for some other reason is unclear; however, it remains an interesting note that none of the parents in the present study indicated that they would alter their situations, given an alternative. Indeed, several parents felt upset that other adults viewed them with pity. The parents interviewed for this study do not in any way view themselves, or their children, as being worthy of pity; in fact, several parents explained that what they most desired for their children was as “normal” a life as possible. To that end, these parents seemed to take pride in treating their children no differently, with the same set of consequences and desires for their success, as any parent would treat a non-disabled child.

As far as respite is concerned, the parents interviewed for this study seem to be aware of both a serious need for, and inability to obtain, all of the respite services they might wish were available. As it has been shown previously that there are several hundred thousand families on waiting lists for respite care services, this finding is hardly surprising. However, the desire for respite services, and the parents’ obvious enjoyment

of and satisfaction with the respite services provided by Camp LIFE, show that whatever these parents may feel is lacking in respite care, it is not due to the quality of care provided by this specific therapeutic camp. In addition, this study attempted to fill a hole in the body of knowledge, which is the examination of overnight therapeutic camps as respite care providers. In that area, the parents were in unanimous agreement: Camp LIFE has successfully accomplished its goal of providing safe and enjoyable experiences for its campers, which in turn allows the parents to fully enjoy their respite weekend activities.

The processes by which camp allowed its campers' families to experience respite free from stress were two-fold: the parents stated that they felt comfortable with the camp facility, staff and medical personnel; and that camp provided a safe and enjoyable experience, during which they learned new life skills, formed friendships, and got to be "just kids". These two processes drove the outcome of enjoyable respite care for each parent, and while the experiences explained by each parent were different, the overall effect was the same.

Respite care, as evidenced by the interviews in this study, is a needed aspect of holistic care for families of children with special needs. Given that providing care for a child with a disability can be a hectic, difficult, and ultimately life-changing experience, the opportunity to "recharge", as several parents described it, was found to be extremely rewarding by all of the parents interviewed. Pearlin's (1990) model can again be used to explain this trend, in that parents utilized respite care in order to adapt to stressors and issues related to caregiving. Without the respite provided by Camp LIFE, these parents

would never get a break; as one parent mentioned, her son was either with her at night, or at camp. Thus, the break from caregiving, small as it may be, is vital in terms of allowing parents to relax and focus on themselves and their own needs. This helps them feel more competent as caregivers, which hopefully ultimately allows them to become more conscientious and loving parents.

Suggestions and Recommendations from Parents

The final question asked parents whether they had any suggestions to improve the provision of services that Camp LIFE provides. The following examples are some of the ways parents thought the camp could increase the efficacy of service provision, although as previously stated, every parent interviewed was highly satisfied with Camp LIFE as a whole, and many of them stressed that these suggestions were specific only to their own children. One example, from Erin, was that parents be able to write a short note to their child's counselor which detailed any specific information they wanted to ensure came across, since during the check-in process she had forgotten to explain a few details regarding her child's condition:

It was hard because it's a learning experience for the students who are going to be the counselors and we're providing the children for them to learn it and give them fun, and give us respite. So somehow...you will learn to how to do this stuff and continue have to do it. And you learn from when they are baby and there are particular idiosyncrasies. So somebody's not going to take on that stuff and they have, and just from talking to them for an hour. So you don't in turn expect them to do every little thing you would do to or for them to...but it would be good to be able to write that down so that if I forgot, the counselor would still know what's going on with my child, the way they're acting. [4:14 385-390]

Rebecca stated that with her own son, having the ability to write a short note to the counselor could mean the difference between a great and a miserable weekend:

Yeah, because like I told you, when I got there, the main thing I wanted the counselor to know was if my son starts acting out, then he's overstimulated, let him have some alone time. I didn't know how he would do. And so, it can be a miserable weekend for him and everyone else around him if you don't take that five or ten minutes to let him have some quiet time. So yeah, that would have been great to have that opportunity to have it on paper. [6:26 381]

Mary related that her child seemed to "get bored" with camp activities, because they had not altered from year to year:

But I'm just like...I just think Camp LIFE, if there's some way that they can mix it up and I know they do. I know they probably do things that I don't even know about but just keeping it for the return campers, keeping new activities. It would be like if you went to a camp several times for during the year. And it's really the same things over and over, would you really want to go back? So I think with my son, it was kind of like I've been there done that. Whereas to us, we're like, "No, you have to go and you have to enjoy it and it's fun" and you know...There are other things like the rock climbing and the zip lining and the horseback riding and all that. He's just, you know, I know he's all over that.

Another suggestion, from Ashley, was regarding buses to and from Bryan /

College Station to the Camp LIFE facility:

The only thing I could see different that would really help out my situation, maybe others, I don't know, is where...because a lot of kids do come from Bryan-College Station area. If they have like, before other camps that my other kids have gone through, a bus picks them up and drops them off at a location, instead of everybody having to drive. And come back where you just check them in here and then they brought them back. And I think that would help out a lot. [1:31 330:334]

A final suggestion was provided by Rebecca and Nicole, who mentioned that they would like for Camp LIFE to set up an e-mail listserv, or even allow parents whose children attended Camp LIFE to opt-in to a Facebook group and exchange information regarding local issues with receiving school support, informative websites or books, or just to provide emotional support:

Rebecca: I would say that a networking through email would be great, just

- because I mean even like a...
- Nicole: Blogs and stuff like that.
- Rebecca: Yeah, I mean with the autism, I found that a few books that I really, really, really like, there are some like I didn't agree with or some I did. So yeah, check this book out.
- Nicole: Well, even with what, some of the battles that we've gone through with the school...
- Rebecca: And you think about it, you're talking about this respite care, the e-mail stuff is great. To meet as a group is so hard when you have kids with disabilities because they got to have the kid so...
- Nicole: Well, emails or...like on Facebook or something like that where we create an account or have just a group that people know where to go when they look at the wall.

This final suggestion was one that seemed to particularly interest both Nicole and Rebecca; it would be interesting to see whether there is any interest in such a group from other parents whose children attended Camp LIFE.

Erin noted that being able to write a note to her child's counselor would be useful use, because she often forgot to mention things to the counselor in the hectic atmosphere surrounding camp check-in. This viewpoint was shared by several parents, who agreed that while they thought check-in was as easy as it could possibly have been, they felt that its very nature meant that they might forget to mention something that could be of critical importance to their child's experience at camp. It might be noted here that at other camps which I have been a part of (for non-disabled children), the ability for parents to write a short note to the counselor explaining any child-specific issues that might arise (bed-wetting or homesickness, for example) was very useful in personalizing and maximizing the experience for each individual camper. As noted in the section on personal bias, I have worked at summer camps before, and found the notes from parents to be extremely beneficial; however, I strove to remain neutral in attitude and conduct

towards these interviews, and tried to refrain from commenting on my own personal beliefs about this suggestion.

Another suggestion, given by Mary, was that Camp LIFE alter the activities it offers from session to session; this seemed particularly pertinent for children who had attended camp multiple times. Since these children often do not have the inclination or ability to participate in “mainline” sports or team activities (football or dance team, for example), allowing them the freedom to pick from a wider range of activities, or at least choose a few activities to participate in more frequently, might be an area worth exploring. This suggestion, of course, is subject to the availability of camp personnel to adequately staff each activity, and since these children do require a higher level of supervision than their non-disabled peers, such an opportunity might be difficult to put into practice. In addition, Camp LIFE must strive to provide as equal an opportunity for all participants as possible and allowing children to participate in activities seen as “high-demand” might cause friction between campers. However, one way to perhaps alleviate this problem is to gauge camper preference for certain activities, and alter the schedule based on which activities are most in demand. However, as was mentioned at the beginning of this section, any possible solutions made to work with parent concerns must be made by Camp LIFE staff, and are subject to the demands and capabilities inherent in the camp experience.

A final suggestion, mentioned during the two-person interview with Nicole and Rebecca, was that Camp LIFE offer to set up an e-mail listserv, or allow parents of campers to join a blog or message board that focused on issues related to parenting a

child with a disability. This suggestion seemed to be important to both women, since both expressed displeasure with the amount of information they received from local sources, such as schools, regarding services for children with disabilities. Both of these mothers seemed to think that if they were able to connect with other parents who were in a similar situation (especially given that they were localized to the Bryan / College Station area), that they would be able to both obtain and disseminate information regarding a wide range of topics, from books they found helpful, to ways of working within the system to obtain services for their children from local sources. I am unaware of the legal ramifications of providing a Listserv opportunity for parents of children who have attended camp; however, such an issue might be sidestepped by simply giving parents the option of “opting-in” to such a group or Listserv, thus reaching only the parents who felt comfortable sharing their personal information. Since several parents mentioned that they worried about their child receiving appropriate local services, such a tool might prove invaluable in enabling parents to work together to achieve common goals. This tool might also serve to give parents a forum for expressing emotional support, or foster the exchange of information regarding child-care or respite care services.

Study Limitations

There are several limitations inherent in this study. First, the sample size was small (n=9), which necessarily limits the generalizability of the findings for this study. Second, the parents were interviewed several weeks after their child returned home from camp, so the ability to recall exact feelings and experiences might have been limited.

Third, as has been noted, the study participants were self-selected, and chose to contact me in order to be part of the study; this might have had an effect of skewing the study sample towards parents who naturally felt inclined to be more participative and focused on care in their child's life. Finally, the disabilities of the children attending camp were not examined in this study; several of the children were subject to the same disability, which might have influenced the parent's beliefs about disability in general, and respite care in particular.

Suggestions for Further Research

This study seems to be consistent with findings from previous research on the subject of respite care, with one exception: while the parents interviewed for this study did recognize the inherent difficulties they faced in parenting a child with a disability, they were quick to point out that they felt no desire to alter their situation, nor did they view parenting a child with a disability in a negative light. This is, as has been stated previously, in opposition to other research, which found that higher levels of parental stress could lead to a desire to leave the situation, or even institutionalize the child (Blacher & Bromley, 1990). The reasons for this discrepancy are beyond the scope of this study, but it would be interesting to see if the viewpoints expressed by the parents interviewed here are held by parents of children exhibiting more serious forms of disability; that is, whether the severity of the disability has an effect on parental feelings of adequacy or desire to continue in a parenting role. In addition, further research should examine closely the processes by which therapeutic camps provide a safe environment for respite care to take place, since only when parents are comfortable with leaving their

child at a camp will they be able to maximize their respite care experience. Exploring specific camp practices that maximize respite benefits (which in turn help increase family functioning) is vital to understanding how camps support families. Only by studying more therapeutic camps are researchers going to be able to recognize which practices are most beneficial in terms of increasing benefits for children, specifically, and families in general. This study began to explore those issues, but more research is certainly warranted in this specific area. Another area of potential further research is in examining how long the benefits from respite care lasted after camp was over and the child returned home. This study found some anecdotal evidence that respite benefits lasted for at least a few days after the child returned home, but did not examine in depth the length of time those benefits lasted, or how respite benefits gained during the child's absence were translated into benefits that were usable once the child returned home. For example, one parent mentioned that she was better able to handle the pressure of daily stress once her child returned home, given that she had been able to get more sleep and "recharge her batteries". Future research should focus on how long these "after-camp" benefits last, what benefits they provide for parents and family, and how to extend them as long as possible past the time the child returns home. Finally, future research should attempt to tease out specific information regarding age and disability type: whether a child's age influences his or her parent's ability to enjoy respite, and what effect the type of disability has on views towards and utilization of respite care services.

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